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# **How do patients with cancer pain view community pharmacy services? An interview study.**

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All authors declare no competing interests

## **Abstract**

Pain experienced by many patients with advanced cancer is often not well controlled and community pharmacists are potentially well placed to provide support. The study objective was to explore the views and experiences of patients with advanced cancer about community pharmacies, their services and attitudes towards having a community pharmacist pain medicines consultation.

Purposive sampling of GP clinical information systems was used to recruit patients with advanced cancer, living in the community and receiving opioid analgesics in one area of England, UK between January 2015 and July 2016. Thirteen patients had a semi-structured interview which was audio-recorded and transcribed verbatim. Data were analysed deductively and inductively using Framework Analysis and incorporating new themes as they emerged. The framework comprised Pain management, Experiences and expectations, Access to care and Communication.

All patients reported using one regular community pharmacy citing convenience, service and staff friendliness as influential factors. The idea of a community pharmacy medicines consultation was acceptable to most patients. The idea of telephone consultations was positively received but electronic media such as Skype was not feasible or acceptable for most. Patients perceived a hierarchy of health professionals with specialist palliative care nurses at the top (due to their combined knowledge of their condition and medicines) followed by GPs then pharmacists. Patients receiving specialist palliative care described pain that was better controlled than those who were not. They thought medicines consultations with a pharmacist could be useful for patients before referral for palliative care.

There is a need for pain medicines support for patients with advanced cancer, unmet need appears greater for those not under the care of specialist services. Medicines consultations, in

principle, are acceptable to patients both in-person and by telephone, the latter was perceived to be of particular benefit to patients less able to leave the house.

**Keywords:** cancer, pharmacy practice research, palliative care, needs and experiences of cancer patients, community pharmacy, medicines.

### **What is known about this topic**

- Pain in advanced cancer is often complex, rapidly changing and poorly controlled.
- Patients with cancer pain rarely access community pharmacy medicines consultation services.

### **What this paper adds**

- Patients without access to specialist palliative care services appear to need more support with their pain medicines.
- Patients are open to the idea of medicines consultations with their community pharmacist in person or by telephone.
- There is concern that the addition of community pharmacists into the palliative care pathway could cause conflict between or duplication of services.

### **Introduction**

Three quarters of people who die from cancer will have experienced pain and it is the most common reason patients with cancer contact out-of-hours services (IMPACCT 2016, Adam 2015). Pain is less well controlled among patients living in community settings compared with those in the hospice or hospital (VOICES 2014). Cancer pain is complex and often changes rapidly with disease progression (Hackett 2016). Many patients increasingly want to spend their last days and weeks in their own homes which has created an increasing need for community-

based patients to be better supported to ensure they receive pain management (Closs 2009, Bennett 2009a, Adam 2015). Community pharmacies are situated in every locality and are often open up to 100 hours a week giving patients free and easy access to a healthcare professional without the need to wait for an appointment however they are widely thought to be an underused resource as many patients often don't realise they can be a source of medicines information (Bennie 2013).

In the British National Health Service (NHS) community pharmacists are funded to provide patient-centred medicines optimisation services that could support patients with less well-controlled cancer pain. However the sparse research in this area found that these services are rarely carried out with this patient group (Savage 2013). Medicine optimisation services currently available in community pharmacies in England and Wales include the Medicines Use Review (MUR) and the New Medicine Service (NMS). MURs are consultations with patients where all patient medication is discussed and explained and often issues around concordance, compliance and supply are addressed. NMS concentrates on newly prescribed medicines and involves two consultations (usually by telephone) to ensure medicines are started and no side effects or problems ensue. There is RCT evidence that NMS detects adverse effects from medicines, positively influences prescribing and improves treatment adherence (NMS Evaluation 2014). A recent review of the limited evidence relating to MUR concluded that "in line with their intended purpose, patient knowledge and self-reported adherence may improve following MURs" (Wright 2016 p37).

Current policy allows community pharmacists to carry out MURs with patients living with cancer pain, but the NMS service can only be provided for patients being newly prescribed medicines for certain conditions; cancer and pain are not included (PSNC 2017). MURs are intended to be provided face-to-face when a patient is in the pharmacy unless permission is requested on an individual patient basis from NHS England (PSNC 2017). Patients with advanced cancer may not

come into pharmacies and their medicines are often collected by relatives or supplied by delivery drivers (Savage 2013).

Where medicines optimisation interventions have been carried out with patients suffering from cancer pain there is evidence of benefit; systematic reviews of educational interventions for cancer pain (by any healthcare professional) found a reduction in average and worst pain intensity. Pharmacist educational interventions for patients with chronic pain showed a reduction in pain intensity, adverse events and an improvement in satisfaction with treatment (Bennett 2009a, Bennett 2011). There are no systematic reviews of pharmacist interventions for cancer pain as very few studies have ever been carried out and no RCTs.

Community pharmacists are the health professional with whom patients with cancer pain have most frequent contact alongside palliative care nurses with 75% of patients having contact within a 2 week period (Bennett 2009b).

Community pharmacists can currently access only limited information about their patients and they do not routinely know which of their patients have cancer. A previous study with community pharmacists found that little communication occurs between them and other healthcare professionals about the care of patients with cancer with pharmacists rarely finding out the diagnosis of the patients whose medicines they were dispensing (Savage 2013). The introduction of Summary Care Record (SCR) access for community pharmacies in 2016 has improved information sharing but not all prescribing is recorded and diagnoses are rarely included.

Research on community pharmacists' views about providing services for patients with cancer indicates a perceived lack of knowledge and need for training (Savage 2013, O'Connor 2013). However little research has investigated how patients with advanced cancer use community pharmacies and attitudes towards having medicines consultations.

## **Aims**

- To explore the views and experiences of patients with advanced cancer about community pharmacy and its services and the associated challenges they may face.
- To investigate the acceptability of community pharmacy medicines consultation services and find out what patients with cancer pain might need from such a service.

## **Method**

A qualitative method of semi-structured interviews was chosen as the study topic was complex and so far unexplored (Bowling 1997). Following a review of the literature the interview schedule was developed in-line with the study aims. Topics included current interaction with pharmacy, services and experiences of them and views on potential future services (see Supporting Material: Table 1). Interviews were semi-structured in design to ensure focus on the research aims whilst allowing in-depth discussion on points of interest. The interview was piloted with two patients and minor amendments to language were made.

This research is part of the wider IMPACCT (Improving the management of pain from advanced cancer in the community) programme which is a multi-disciplinary body of work involving Leeds, Bradford and York Universities. Ethical permission was granted from Leeds West Ethics committee.

### *Sampling and recruitment*

Purposive sampling was carried out to ensure focus on the views of patients experiencing pain from advanced cancer. The assumption was made that patients would have some involvement/contact with community pharmacies through dispensing of prescribed medicines.

The inclusion criteria for patients were:

- Aged over 16 years
- Have advanced cancer\*, are aware of their diagnosis and are experiencing pain
- Have been prescribed a strong or moderate opioid for cancer pain within the last three months\*\*
- Have not been prescribed anticipatory medicines and are not considered to be in the last days of life
- Have capacity to provide informed consent
- Have capacity to complete questionnaires before and after the medicines consultation.

\*People with advanced cancer are those with metastatic cancer with histological, cytological or radial evidence and/or those receiving anti-cancer therapy with palliative intent.

\*\*Strong and moderate opioids are codeine, codeine and paracetamol, codeine and ibuprofen, dihydrocodeine, paracetamol and hydrocodeine, tramadol, tapentadol, morphine, fentanyl, buprenorphine, diamorphine, hydromorphone, methadone and oxycodone.

Patients were recruited from GP practices in one area of England between January 2015 and July 2016 to take part in an interview with a researcher. Research-ready practices which employed a practice pharmacist were selected from areas of differing deprivation scores within the area to represent the wider population (Open Data Communities 2015). The researcher was not allowed direct access to the practice clinical information system so practice pharmacists carried out searches. Letters of invitation were sent to the practice manager, with telephone



follow up by ZE and meetings were arranged to discuss the research where the practice wished to do so. 21 surgeries were invited to take part and 16 agreed to do so.

Each practice pharmacist carried out a pre-designed search of the practice clinical information system to identify patients who had any cancer code attached to their record. The practice pharmacist then individually searched the patients' record to check whether their cancer code was current and they had advanced cancer.

For those patients identified as being potentially eligible to take part, a task was sent to their GP to ask whether they were suitable for inclusion in the study i.e. they had capacity to provide informed consent and had not deteriorated since the search. A letter of invitation, participation information sheet and consent form were then posted from the surgery including details of the research pharmacist, why the research was being carried out and what would happen.

Completed consent forms were returned to the research pharmacist at the university.

Reminders were not sent as the health of this patient group is likely to change rapidly leading to changes in eligibility.

The target sample size was 15 patients or when data saturation was reached (Malterud 2016 , Fusch 2015).

#### *Data collection*

The interview guide was developed using the aims of the study and is available as a supplement to this paper (Supporting material: Table1). Participants were given the choice as to where they would like the interview to be carried out and were asked if they would like to have a family member or carer present with them during the interview. The research pharmacist carried out the majority of interviews with a second researcher helping when the research pharmacist was unavailable. Although the research pharmacist had limited experience of interviewing, they had extensive consultation experience and were supported by a highly experienced research lead

and wider group. Following each interview the researcher carrying out the interview wrote reflective field notes to support analysis. Patients were recruited and interviewed until two interviews after no new themes emerged, at which point it was concluded that data saturation had occurred (Fusch 2015).

### *Data analysis*

Interviews were audio recorded and transcribed verbatim before being analysed using thematic Framework analysis by the research pharmacist (Ritchie and Lewis 2003). This method was chosen as it allows analysis across participants leading to the development of meaningful themes whilst still allowing the context of each individual taking part (Gale 2013, Smith 2011). A combined approach of inductive and deductive analysis was used. We were interested in pharmacy use in patients with cancer pain however we wanted the qualitative interview data to inform our themes and allow unexpected findings to be explored (Gale 2013).

Interview transcripts were read and re-read by ZE and AB to gain familiarity alongside field notes from both researchers (ZE and MA) following which a framework was developed. The framework was then applied to the data. Data was then sorted into similar concepts before being summarised. Descriptive categories were then allocated and refined by ZE, AB and BF several times until the authors were satisfied with the themes and sub-themes assigned.

In the Results section which follows the verbatim quotations from participants are coded using a site-code (S) and a patient number code (P). C corresponds to a carer or family member who was involved in the interview.

## Findings

In total 121 patients were identified from searches of GP clinical information systems and subsequent individual review of notes. GP's assessed seventy-three patients were suitable for invitation and were sent an invitation pack.

Thirteen patients returned a completed consent form and agreed to be interviewed (from 7 of the 16 surgeries) and all requested the interview to take place in their own home. Patients were aged between 40 and 89 years old; 10 were male and 3 were female and they lived in areas with deprivation scores of between 2 and 10 (Open Data Communities 2015). Interviews lasted between 27 and 51 minutes and none were repeated. Saturation of themes was apparent after the eleventh interview. Table 1 summarises key characteristics of the patients in the study. Three patients were interviewed in the presence of family members who also contributed to the discussion.

**Table 1: Patient characteristics**

Patient	Gender	Age years	Depriv- ation score of postcode*	Employment status	Social circums- tances	Comm- unity Pharmacy Use	Under specialist palliative care services	Awareness or experience of community pharmacy medicines consultation services
S1P1*	F	89	6	Retired	Lives	Regular	No	No
**					alone			
S1P2*	M	68	6	Retired	Lives	Regular	No	Yes
**					with partner			
S1P3	M	81	6	Retired	Lives	Regular	No	Yes

					with partner			
<b>S2P1</b>	M	61	2	Employed Off sick	Lives alone	Regular	No	No
					alone			
<b>S5P1</b>	M	68	10	Employed	Lives alone	Regular	Yes	Yes
					alone			
<b>S5P2</b>	M	70	10	Retired	Lives	Regular	Yes	No
					with partner			
<b>S5P3</b>	M	82	10	Retired	Family staying	Regular	Yes	Yes
					staying			
<b>S5P4</b>	M	52	10	Employed Off sick	Lives with family	Regular	Yes	No
					with family			
<b>S7P1</b>	M	50	4	Unemployed	Lives alone	Regular	No	Yes
					alone			
<b>S8P1</b>	M	58	10	Retired	Lives	Regular	Yes**	Yes
					with partner			
<b>S10P1</b>	M	77	6	Retired	Lives with partner	Regular	Yes	Yes
					with partner			
<b>S13P1</b>	F	55	6	Employed	Lives	Regular	No	No
					with family			
<b>S13P2</b>	F	40	6	Employed Off sick	Lives with family	Regular	Yes	No
					with family			

\*Deprivation scores where 1 is the most deprived centile and 10 is the least (Open Data Communities 2015).

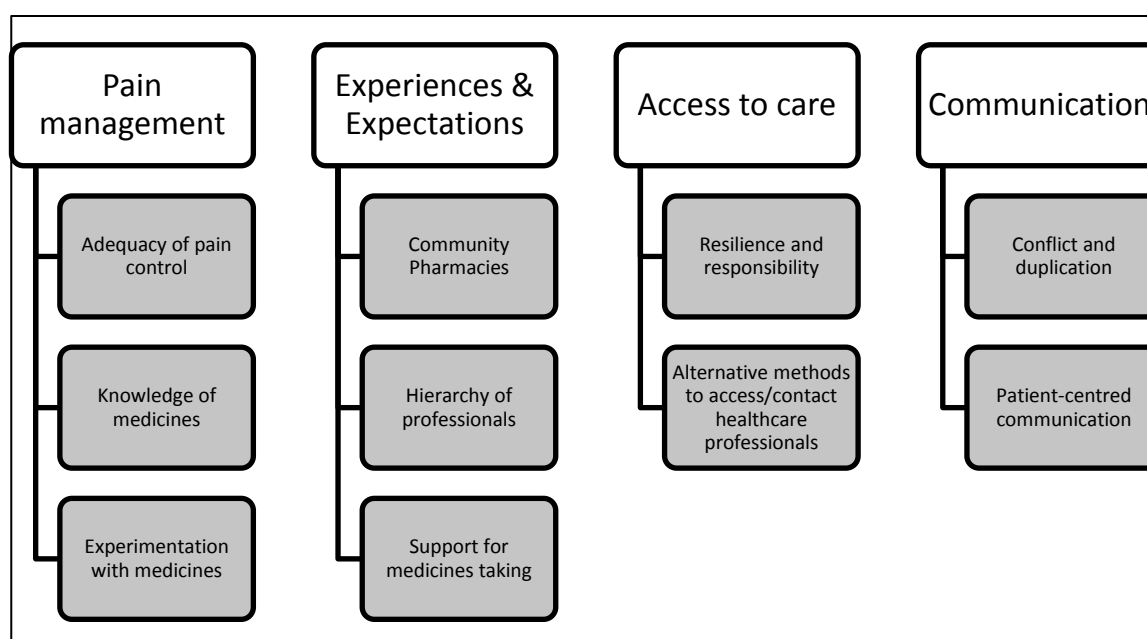
\*\* In regular contact with Hospital ward nurses.

\*\*\*Interviews carried out by MA. All other carried out by ZE.

### *Interview findings*

Ten sub-themes were identified from the analysis (between two and three per theme) (Fig. 1)

**Figure 1: Summary of themes and subthemes found in qualitative interviews with patients suffering from advanced cancer exploring use of pharmacy and its services.**



### **Pain management**

#### *Adequacy of pain control*

Pain levels and reported adequacy of pain control varied considerably among the patients.

Those receiving specialist palliative care appeared to be more comfortable with how to manage their pain and who to turn to for help. They explained how their medication could be changed in a timely manner in response to changing needs.

The patients who were not receiving specialist palliative care services seemed to have pain that was less well controlled.

### *Knowledge of medicines*

Some patients were very knowledgeable about their pain medicines while others appeared to know little and voiced a need for more information that could give them practical advice on how to get the best from their medicines.

Some patients did not realise that they had insufficient knowledge to be able to use their medicines to manage their pain and were unsure of which medicine was being used for which symptom. One patient did not know what their MST (morphine sulphate prolonged release) tablets were for. It seems unlikely that this patient would be able to adequately control their fluctuating pain levels with regular and top-up medication without a better understanding of their purpose.

### *Experimentation with medicines*

Experimentation through reducing the dosage taken was sometimes in response to concerns over addiction and tolerance (where a patient believed that the medicine might become less effective if taken over a period of time). Some patients were uncomfortable with their 'tablet burden' and wanted to reduce medicine taking to the lowest possible level that would still control symptoms.

Occasionally professionals were reported to have been dismissive of patients' fears and anxieties, leading to patients not seeking further advice from them. One patient had tried to voice their concerns about taking too much pain medication to their healthcare professional and went on to reduce their medicine taking on their own.

## **Box 1: Pain management**

### *Adequacy of control*

"...if the pain gets more severe, I'll ring [the Macmillan nurse] up and say I can't go on like this!

[The nurse says] ok, we'll talk to the doctor, increase the dosage of the patch." S10P1

"Every day up to a point... there's something, some pain somewhere...they've referred me somewhere. Don't know where." S7P1

### *Knowledge of medicines*

"I just wish sometimes that there'd be a little sheet really almost that sort of said you know do this, do that" S13P1

"So you take MST as well?" Interviewer

"That's it yeah...Is that a painkiller?" S1P1

### *Experimentation*

"I'm always experimenting actually...I don't know if that's a good thing or not." S13P1

[The doctor said] "we can see that...there isn't a right lot we can do about it, you know you just have to [take them]. S8P1

## **Experiences and Expectations**

### *Community Pharmacies*

All patients interviewed reported using one regular community pharmacy (one, also additionally used a hospital pharmacy regularly at outpatient visits for specially prescribed treatment).

Pharmacy location was important, sometimes through convenience and the pharmacy's proximity to the patient's GP surgery. Some patients talked about a preference for independent pharmacies rather than chains.

One patient had limited mobility and spoke about having to leave plenty of time to walk to the bus stop before catching the bus to the GP surgery. Using the pharmacy next to the surgery made their life much easier.

Service was also an important factor for patients in choosing which community pharmacy to use and several patients had changed pharmacies after repeated perceptions of poor service.

In contrast some patients described having 'good relationships' with their community pharmacy team. Examples of how these relationships manifested themselves were where pharmacy staff knew the patient's name or were reported to have gone "above and beyond" what might be expected from them.

Patients felt that occasional problems with pharmacies such as mistakes or stock issues could sometimes be forgiven if they perceived the staff to be friendly and trying their best.

The positive experiences were not without exception and lack of relationship rather than a negative relationship was expressed.

Patients seemed to value more than just the basic level of service from their community pharmacy and wanted to be treated with friendliness by staff who knew them. This attribute positively influences the continuity of pharmacy use.



### *Hierarchy of professionals*

Patients perceived a hierarchy of professionals with whom they came into contact in primary care depending on who was involved and the stage in their cancer journey they were at (e.g. diagnosis, treatment, non-treatment and palliative care). Those patients who were under the care of specialist palliative care services would, without exception, always refer any problem to them.

One patient believed the specialist palliative care nurse had more expertise about cancer than GPs as well as dealing with cancer pain on a day-to-day basis

The GP was viewed as second in line to go to for advice, or first in line if the patient did not have access to palliative care advice.

The community pharmacist was mentioned by one patient as being an option for advice.

One patient who reported positive experience of clinical interventions questioned the capability of community pharmacists to provide advice as they may have less knowledge about medicines than doctors.

### *Support for medicines taking*

Patients were introduced to the idea of a community pharmacy medicines consultation to support medicines taking. Although seven patients were aware of community pharmacy services, only three had experience of them and none of these had been since their cancer diagnosis

The need for support was felt more by those were not receiving palliative care services and therefore did not have direct access to advice from palliative care professionals.

Patients were positive about the prospect of receiving community pharmacy services to help with their medicines use but many saw that as being the role of their GP.

The patients described how their medicines and doses had changed over time, making support after a medicine is prescribed - important and useful.

## **Box 2: Expectations and experiences**

### *Community pharmacies*

"It's our local pharmacy because it's the nearest....and it's right next to the GP. So if the GP gives you a prescription . . . . you just pop into the pharmacy next door. Its...the whole experience of supporting your local community...rather than a big chain." S5P4

"[The pharmacy] is directly opposite the doctors it's the easiest one...I get my prescription then I can just walk over and get it there." S7P1

"[the other pharmacy] didn't seem to like over stocking so it was always having to go back for the owing note... it was also the unfriendliness of the staff" S5P2

"They're lovely... I erm got there to pick my medication up and one of the pharmacists, he says are you alright? I says no I'm not so I told him what my problem was. He says have you a minute so I can talk about it and he sat down with me...they really are very nice. S1P3C

"But they're smashing and I mean sometimes they do leave stuff off or forget stuff or whatever...but I mean they are really, really good I mean I've never had any bother with them" S8P1

"They're not rude but at the same time they're not overly friendly" S13P2

### *Hierarchy*

"I don't see the doctor...I deal with the Macmillan Nurse....[they] visit me regularly erm I've no doubt I'll be seeing [them] next week, [they] just phone up and ask if it's ok to come along er, I just can't fault [them]." S5P2

"Before you were in touch with [the palliative care nurse], was there anyone else you'd speak to?" Interviewer

"Straight to the doctor" (640) S10P1

"If I couldn't get into the doctor I'd ring the pharmacy" S1P3

"Because they can be very helpful can the pharmacists but they might not, I mean they aren't qualified doctors so they might just give you something thinking they were very helpful and you might take it and it might upset the cart..." S1P1

### *Support for medicines taking*

"If I were offered [a community pharmacy consultation] then I wouldn't take it up because I prefer to speak to my doctor... who knows more about me than anyone else" S5P3

"Well [they] can't tell me about that, it's got to be my cancer specialist (nurse)" S2P1.

"I was thinking that this week, thinking I'd really like to just talk to someone and say is it OK to just do this and take that every day once a day without taking Lansoprazole or is that going to

really affect my stomach, you know it's like I don't know the answer to that so there's lots of questions around it." S13P1

"I'm just still in a lot of pain" S7P1

"What do you do when that happens? Who do you talk to?" Interviewer

"Erm, I just sort of struggle through" S7P1

"I think that's a good idea...and it would be good to review that occasionally. But I thought that would be done by the doctor who is, is treating you." S5P4

"It's quite a good idea ... especially with the cancer medication and they do have a lot of side effects and sometimes even if they discuss the side effects... when you're experiencing the side effects, you do wonder [should it really be] as bad as this?" S13P2

## **Access to care**

### *Resilience and responsibility*

Patients talked about problems they experienced with managing supplies of their medicines and strategies they used either at the time or developed following an incident to prevent it happening again.

Early ordering of prescriptions to allow the pharmacy time to order items not in stock was a common way to prevent a patient from running out of medicines.

When a patient was seen by a doctor outside of usual working hours this posed particular challenges. One patient explained about a time they had been given a prescription for

emergency painkillers at 2am and there was no community pharmacy open where it could be dispensed.

The prescribing doctor was not able to suggest a solution, and it was only afterwards that the patient thought of a different way that they might have been able to get the medicine.

#### *Alternative methods to access/contact healthcare professionals*

Patients were familiar with contacting healthcare professionals by telephone and many described ordering medication by phone or ringing community pharmacies with queries. Most patients would accept medicines consultations with their pharmacist by telephone, and some thought that this method would be easier due to mobility problems or trying to fit in multiple health appointments around other commitments.

Some patients preferred face-to-face contact with a healthcare professional and one raised potential communication difficulties which may occur with telephone conversations.

Patients were also asked how they felt about the possibility of using electronic devices (computers, smartphones etc) to access healthcare professionals using tools such as Skype or Facetime. Four patients responded positively however, most of the patients voiced their lack of access to computers or computer literacy as reasons for not wanting access in this form.

#### **Box 3: Access to care**

##### *Resilience and responsibility*

“If I was very late with any prescription it was usually [the pharmacy’s] delivery that was [the problem]. It wasn’t [the pharmacist’s] fault, do you know what I mean. Yeah so I worked it so I was ordering like a week to two weeks before I actually needed it” S5P1

"The pain was so bad, excruciating and at that time we couldn't get hold of any medication. Went to [two neighbouring towns]. (The prescriber) said [they, they didn't] think there are any pharmacies open.....I think you know in hindsight I think I should have just gone to A & E because that's so bad, because you know the pain was so bad I think, nobody believed me that it was so bad." S13P2

*Alternative methods to access/contact healthcare professionals*

Talking about a community pharmacy consultation "But then what I'm thinking is then it's another drive, it's another appointment, it's another appointment to deal with is what I'm thinking." S13P1

"What about if it was done by telephone?" Interviewer

"Yeah, that would be alright...I really wouldn't want to have to drive to another appointment. You know it's bad enough fitting everything in as it is really around working and living." S13P1

"I would very much prefer face-to-face contact....Em over the phone is possible as well but the medication... is, it's, it's.. they all have these fancy names and you need to have to, you can't remember it!... But em...you need to be very organised and have a list and have it all written down and pronounce them all correctly and stuff" S5P4

"I haven't got a computer and I don't want one." S1P1

"We're not that technical....we'd rather just go and talk to somebody." S1P2

**Table 2: Patients' ownership of technology and acceptability of different methods of service provision**

Patient	Use of computer	Acceptability of telephone consultation	Acceptability of Skype consultation
<b>S1P1</b>	Not owned	Acceptable	No access
<b>S1P2</b>	Owned	Prefers face-to face	Lacks technical ability
<b>S1P3</b>	Owned	Acceptable	Lacks technical ability
<b>S2P1</b>	Owned	Acceptable	Not acceptable
<b>S5P1</b>	Owned	Acceptable	Not acceptable
<b>S5P2</b>	Owned	Acceptable	Not acceptable
<b>S5P3</b>	Not disclosed	Not acceptable	Not acceptable
<b>S5P4</b>	Owned	Prefers face-to-face	Acceptable
<b>S7P1</b>	Not disclosed	Acceptable	Not disclosed
<b>S8P1</b>	Owned	Acceptable	Acceptable
<b>S10P1</b>	Owned	Acceptable	Acceptable
<b>S13P1</b>	Owned	Acceptable	Acceptable
<b>S13P2</b>	Owned	Acceptable	Not acceptable

## Communication

### *Conflict and Duplication*

The patients in this study were receiving care from many healthcare professionals and described how they sometimes received conflicting messages.

Where a patient thought they had access to sufficient advice about pain medicines the involvement of an extra person such as the community pharmacist was seen as having potential to introduce further conflicting advice.

#### *Patient-centred communication*

When talking about communication between healthcare professionals, one patient was surprised to learn their community pharmacist did not have access to their records as their perception was that they were a 'safety-net' where all their medicines from different sources were collated and checked. There was an assumption that communication between the different professionals and across care transitions occurred more than it did in reality.

#### **Box 4: Communication**

##### *Conflict and Duplication*

"....trying one thing after another and it isn't working, they've been doing it for years and it isn't working and being told that there isn't an operation they can do to cure it but my GP says there is" S1P2

"I don't like conflicts..... I don't want different people telling me different things... I'm really happy with the Macmillan nurse – I don't want somebody saying [they are] wrong" S5P2

##### *Patient-centred communication*

"The hospitals usually send a letter to your GP don't they? I don't suppose they do that with the pharmacy...ask for it or whatever to be sort of emailed over to them" S7P1

"So if you have been prescribed something in hospital and pick it up from [the] pharmacy, (the community pharmacy) wouldn't even know about it? That's not good! ...But there might be some, some erm...interference or interaction between this new medication and the long list of



## Discussion

This study explored patients' perspectives about community pharmacy services in the context of pain management in advanced cancer. Our findings confirm those of other studies that there is unmet need for additional medicines support for some patients (and their carers) during pain management in palliative care in cancer (Closs 2009, Latter 2016, Bennett 2009a, Adam 2015). Similar numbers of patients in this study were receiving and not receiving specialist palliative care services therefore allowing insight into the needs, experiences and perceptions of both groups.

To our knowledge this study is the first to explore continuity of pharmacy use and the only to explore use by patients with advanced cancer. Patients' views of their community pharmacies varied and most used them only for medicines supplies and occasional advice. Few were aware of medicines consultation services and even fewer had used them. This finding supported previous research which found that pharmacists reported rarely carrying out medicines consultations with this patient group (Savage 2013). Patients provided little evidence of a 'clinical' relationship with their community pharmacist. Instead patients spoke mainly about what they perceived as 'good' service and many had changed pharmacies in the past to obtain the service they wanted occasionally accepting a trade-off where friendly staff were perceived to compensate for inadequacies in reliability and accuracy of medicines supply. Interestingly, all participants had a regular community pharmacy and the choice of this was based on service, location and for some whether it was an independent business or not.

Whilst most patients regarded their pharmacist in a positive light and some quoted occasions where the pharmacist made clinical contributions to their care, the pharmacist's knowledge

about cancer pain and their place in the preferred order of who to contact was low. Patients perceived the need for not only medicines knowledge but also specialised clinical knowledge about their specific cancer and access to their medical history. The ideal support seemed to be in the form of a specialist palliative care nurse who had a combination of knowledge and expertise relating to both medicines and cancer along with access to their medical history. General practitioners were next followed by the community pharmacist. This is in line with findings from a previous knowledge-based study where nurses were found to know the most, followed by GPs and pharmacists with regards to pain assessment in palliative care (Furstenburg 1998). Several other studies have also demonstrated a need for further pharmacist training in palliative care knowledge and issues surrounding difficult conversations (Savage 2013, O'Connor 2013 and Hussainy 2006, Borgsteede 2010). Where pharmacists have been trained to provide community palliative care services in Scotland, healthcare professionals saw them as their 'first port of call' for information about palliative medicines (Akram 2017).

Although this is a small study the findings indicate that patients who are not receiving specialist palliative care seem less able to gain optimal use from their pain medicines and have no timely access to advice in times of worsening symptoms or crisis. This is supported by the Voices survey where only 18% of patients in community settings were likely to describe their pain as being completely controlled compared with 38% in hospital and 68% in hospice environments (VOICES 2014). Referral to palliative care is known to happen relatively late in the journey of a terminal cancer patient and one third of patients who die from cancer never receive specialist palliative care services (Ziegler, 2017). The idea of resilience of the patient to cope with problems has been found in other disease areas, not just palliative care (Fylan-Gwynn 2017). Of course, not all patients want to be referred to specialist palliative care or indeed, have the opportunity to be. Therefore, a need exists for medicines support either before that referral occurs or for patients who stay under the care of their GP.

Most patients found the idea of a community pharmacy medicines consultation acceptable whether face-to-face or by telephone. Patients felt that this would be of most value early on in the cancer pain journey and before the involvement of specialist services. Patients were generally uncomfortable with the idea of medicines consultations being carried out via Skype as there was a lack of access to equipment or unfamiliarity with technology. Patients were more positive about medicines consultations being conducted by phone and found the idea of this less burdensome in-terms of travel and time than a face-to-face consultation. Telephone-based consultations are now carried out on a routine basis with palliative care patients in another area of West Yorkshire (Middleton-Green 2016). There was a gap between the theoretical acceptability and the likelihood of actually using a medicines consultation service in the future.

Patients' need to experiment with their medication to try and achieve pain relief at the lowest possible dose was evident and this could be helped by educational interventions to either optimise the medicines they have already been prescribed, allay any fears or stigma surrounding the use of strong painkillers or to refer to prescribers for a dose change. This is backed up by previous research which found an improvement in pain scores for patients with cancer pain who received educational interventions (Bennett2009a).

### **Strengths and limitations**

We encountered challenges with recruitment mainly due to potential participants being too unwell to participate and therefore views of patients with very advanced disease are not included.

The study was conducted across a single UK city with a diverse socioeconomic population however we recognise the findings may not be transferable to other parts of the UK.

Whilst the average age of participants was 64 years old and the majority were male there is evidence that older patients do not experience cancer pain differently although there is

evidence to suggest that there are gender differences in healthcare utilisation (Bennett, Closs & Chatwin 2009, Wang 2013).

The interviewer was a research pharmacist and their professional background was shared with the participants and potentially influencing the views expressed with a degree of participant eagerness to please and say the 'right thing' and paint community pharmacy in a positive light (Jack 2008). Conversely the background of the researcher aided understanding of issues throughout the interviews and therefore they acted as an 'embedded researcher' (Vindola-Padros 2016). Reflexivity was practiced by the researcher throughout.

At the beginning of the interview process, researchers were unaware of all important issues for the patients with regards access to equipment. This unfortunately, led to a small amount of missing data for computer ownership. We feel that as this was the case with such a small number of participants it does not devalue our findings.

Any qualitative study relies on the interpretation of the data and this may affect the reliability of the results. In the current study this was mitigated by the involvement of other research team members in discussions about coding and during the write up of results.

### **Implications of the study**

Our findings have implications for practice, policy and research. The most effective use of a community pharmacy medicines consultation appears to be for patients who are not receiving specialist palliative care and the pharmacists need to be appropriately trained in both theory and consultation skills to provide such a service. The development of referral pathways to identify these patients is a necessary next step and a pathway from community pharmacy to palliative care could be usefully explored. Based on the findings of the study reported here we have delivered NMS style consultations by telephone to patients with pain from advanced cancer and the results could inform future policy discussions. It is vital that any new service is

designed with the needs of the patients in mind and is accessible for all who need it. Our findings show a need for medicines support for some patients with pain from advanced cancer and that they are receptive to a telephone-based consultation with a healthcare professional.

## **Conclusion**

Patients experiencing pain from advanced cancer have complex and often changing medicines regimens which pose challenges in terms of management and optimisation. This study has shown that patients have unmet needs and indicate that targeted community pharmacist input from highly trained pharmacists as a potential information source for patients is worthy of further research. There is a need for medicines support for patients who have not yet been, or may not be referred to specialist palliative care. Patients receiving care from specialist palliative care nurses valued their expertise and saw them as the first port of call for advice about pain medicines. Patients were receptive to the idea of a medicines consultation with a community pharmacist and were positive about this being carried out in a face-to-face setting or by telephone. Widening access to telephone medicines consultations could contribute to improving access to pain medicines support in advanced cancer.

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